



RESEARCH PROJECT BRIEFING

RESEARCH

INFORMATION

TITLE — Adults' experiences of having Long Covid



AIMS

- To understand the lived experience of people with Long Covid in 2020-2022
- To make these experiences accessible to the public (e.g. people with Long Covid and their families, carers, colleagues) and to health/social care professionals, health care decision-makers and policy-makers via the Health Experiences Insights (HEXI) website.
- To compare experiences of adults with Long Covid across different health care systems, and with people who had other experiences of Covid-19 (e.g. needing treatment in ICU)



KEY FINDINGS

- People who developed Long Covid early in the pandemic ('vanguard patients') found it difficult to live with and make sense of myriad, often bizarre and debilitating symptoms affecting many bodily systems. Their lives were profoundly disrupted and many worried about their future, and the impact on their work and families.
- They often struggled for recognition of their illness in the face of public disbelief and limited scientific knowledge. They often felt invisible to wider society and discounted or abandoned as they tried to find medical help. Feeling 'believed' by health care professionals (HCPs) was very important to patients, even if those HCPs did not know how to treat this novel illness. Some described 'co-experting' with their doctor whilst they worked together to find ways to manage this challenging, poorly understood illness.
- Many had been unable to return to work. Sickness absence policies classifying people as 'able' or 'disabled' were unhelpful for employees with fluctuating, episodic and/or 'invisible' symptoms (e.g. brain fog).
- Young adults with Long Covid felt they had reverted to an earlier life-stage when they needed to return to their parental home for basic care. We have referred to this as 'biographical retrogression' in sociological terms.
- People had no idea when or whether they would recover. Their experiences contrasted with people in intensive care with Covid-19, whose suffering was widely recognised.
- Having a contested condition imposes an additional burden on people.





WHAT DID THE STUDY INVOLVE?

The experiences of 63 people with Long Covid, collected via online/telephone interviews in 2021/2022, are represented on the 'Long Covid in Adults' HEXI website. Participants were initially invited to describe their experiences from when they first fell ill with Covid-19 to the present time. A semi-structured topic guide was then used. Participants reviewed their transcript before assigning copyright so extracts from their interviews could contribute to the HEXI resource. Thematic analysis identified key topics for this website. More detailed analysis included comparison with data from other countries, and other conditions. Our co-investigator with lived experience commented on all stages of the project. An expert panel (which included people with lived experience of Long Covid) advised on the topic guides and provided feedback on early findings and the interim version of the HEXI website.

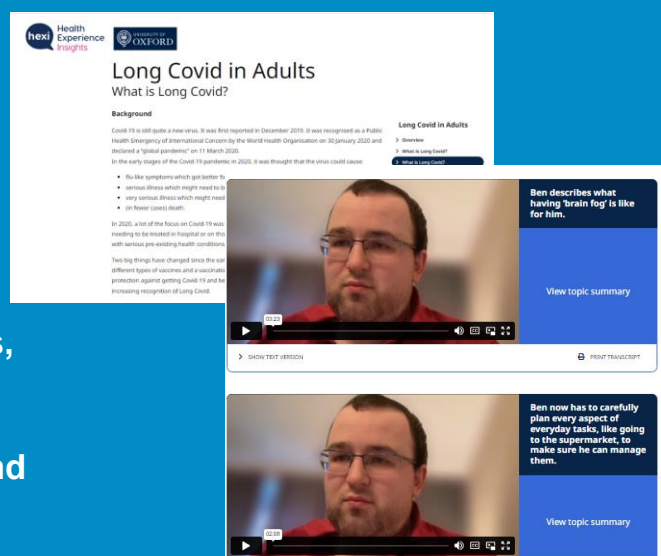


WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

People with Long Covid suffered from strange and incapacitating symptoms, some of which fluctuated over time and were difficult to make sense of. Most participants had been healthy and very active before contracting Covid-19. They described the extra emotional toll of having a new illness and of trying to convey the depth of their distress and the disruption to their lives to health care professionals, colleagues, employees, family and friends. Their physical and neurological symptoms (e.g. breathlessness, profound fatigue, muscle/joint pain, 'brain fog') – and their worries about being unable to return to work and about the future – caused many of them to experience poorer psychological health. Young adults in their 20s described reverting to an earlier life-stage as they lost their adult independence when unable to work and returning to their parents' home for support with their basic needs. Because Long Covid was a new condition there was no scientific evidence base to guide 'vanguard patients' towards the most appropriate treatments or the best ways of supporting their recovery. The absence of scientific information about the long-term prognosis for Long Covid left many feeling profoundly worried about the continuing impact on their working, family and daily lives into the future.

People's experiences are freely accessible as easy-to-read topic summaries, illustrated by video, audio or written interview clips (<https://hexi.ox.ac.uk/Long-Covid-In-Adults/overview>)

The summaries cover a range of topics, such as 'Managing Long Covid day to day', 'Messages for Others', 'Seeking help from health care professionals' and 'Long Covid and work'





WHAT IMPACT COULD THE FINDINGS HAVE?

- Whilst scientific understanding of Long Covid remains sparse, ready access to accessible summaries and first-hand accounts of patient experiences can help policy-makers and health care professionals understand what it is like to have Long Covid. They are also valuable for other groups, such as employers with limited knowledge of Long Covid, and for teaching medical, nursing and allied professional students.
- Patients and their family members/carers can gain support from learning about how others have felt and coped, especially as Long Covid did not exist prior to 2020.



HOW WILL THE OUTCOMES BE DISSEMINATED?

Summaries of people's experience are available on the HEXI 'Long Covid in Adults' website, illustrated by video, audio and written clips. The study team contributed to a complementary NIHR-funded study and HEXI website on 'Long Covid in Families'.

Academic papers to date address: experiences of seeking appropriate health care for Long Covid in the UK and other countries; young adults' experiences of 'biographical retrogression'; the additional emotional burden of having a 'contested' condition; similarities and differences in pathways towards recovery for people with Long Covid and those who had been in ICU with Covid infection; and experiences of trying to return to work following Long Covid.

A new study is addressing the impact of Long Covid on the workforce in four public service occupations: nurses, teachers, police officers and ambulance workers. An allied NIHR-funded study has examined the impact of Long Covid on families.



CONCLUSION

Having Long Covid early in the pandemic (2020-2022) was a unique experience. People's symptoms were devastating and often seemed inexplicable. Because early public messages about Covid-19 stressed it could be fatal, or cause mild and quickly resolving illness, people often felt that the extent of their suffering with longstanding, debilitating symptoms and disrupted lives was questioned by the general public and health professionals. These experiences show the vital importance of listening carefully to patients with novel conditions as their experiences include vital first steps in building an evidence base for scientific understanding and effective treatment pathways.



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Additional Information

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